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ABSTRACT

The paper examines three case studies to illustrate problems and benefits involved in attempting to integrate severely handicapped persons into community and classroom settings. The authors discuss the integration efforts for two children with severe/multiple handicaps and one with autism and report on findings from site visits across the United States and intensive case studies in New York State. Among integration efforts noted are mainstreamed lunch, art, and music groups; shopping as a community skills program for high schoolers; and inclusion of multiply handicapped child into small group kindergarten play. Reluctance of some teachers and administrators is considered along with new ideas of education held by others who have successfully integrated severely handicapped students. Three approaches to education (clinical-treatment perspective, functional life skills perspective, and developmental learner perspective) are discussed, and the advantages to integration of the whole life/functional perspective are stressed. (CL)

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THE CHALLENGE OF INTEGRATING STUDENTS WITH SEVERE DISABILITIES

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INTRODUCTION

New laws, new curricula and new students . . . a lot has changed in education since the passage of Public Law 94-142, (The Education of All Handicapped Children Act) in 1975. Now teachers and parents try to learn how to talk together about "specific objectives"; principals struggle with the "whats" and "why's" and "how's" of related services; faculty members at universities churn out new curricula for students with "severe and profound" disabilities. In some instances, students classified as severely impaired find themselves in typical school settings, interacting with their typical peers -- perhaps for the first time. Children who may have quite severe impairments -- labels may range from "profoundly retarded" to "severely emotionally disturbed" -- go to typical neighborhood public schools. Segregated schools have been closed; children who might have spent their whole education in separate settings, isolated and segregated from typical peers, find themselves fully integrated into a wide variety of school and community settings.

These events challenge some teachers; in fact some teachers do not believe that such "integration" can work with severely handicapped children. "You can't maintain the necessary quality" becomes a refrain. Through interviews with teachers and observations in their classrooms (and community settings), we recount how teachers have struggled with the ideas and practices connected with the integration of children with severe disabilities in typical public school (and community) settings.

The language and the incidents originate from teachers themselves; it is their language, their challenge, their charge. The information about teachers in the United States as well as intensive case-studies of twenty-five sites in the Central New York State region. From the teachers themselves, we heard stories that illustrate the ambiguities, struggles, frustrations and successes that teachers continue to have with children and young people who are severely impaired.

From the hundreds of students we will focus on three throughout our discussion.

The rest of the article describes what students do, shares how teachers feel and presents how teachers talk about educating severely handicapped students.

Michael

Michael is twelve and spends most of his day in an adapted wheelchair. He can push his wheelchair, but it takes a long time to go a few feet. Although he talks some, it's hard to understand him; mostly, he repeats everything you say. He drools, keeps his fingers in his mouth often and needs help eating. Michael likes to watch things around him; he laughs often; and he enjoys being on the floor where he can roll around. Michael is labelled a "severely, multiply handicapped" student.

Peggy

Peggy is eight and cannot walk. She has learned to sit, unattended for nearly five minutes; drinks from a cup (with help) and has started to use a swivel spoon to eat. She spends much of her time in a specially adapted chair; on a mat, she can roll

over, but cannot yet pull herself around. Peggy has weak muscle tone and seems floppy. Small for aged eight, many people think of her as a three-year-old. Socially, she responds to people, flailing her arms up and down. Labels have included "profound retardation, with severe cerebral palsy" and "multiply handicapped."

Robert-Andrew

Robert-Andrew is 17 years old; for fifteen years he lived in the State Psychiatric Center on a special ward for "autistic" children. He bites, kicks and punches people for no apparent reason. He also sometimes scratches and hurts himself in other ways. He is a big person, even for seventeen years old. He has lost most of his hair and has a noticeable facial scar; his hands and arms are large and pronounced. At times, he seems to enjoy people; yet, the next second he may try to punch or bite. He cannot talk but uses a communication board; he seems interested in signing but the teacher isn't sure. In the past, labels have ranged from "autistic" to "severely emotionally disturbed" to "severe behavior disorder."

FINDINGS

More and more, the Peggys' and Michaels' and Robert-Andrews' have begun to show up in regular educational and community settings, with other students their age.

After more than twenty site visits across the United States and another twenty-five intensive case studies in the Central New york State area, we found extensive evidence of integration of students with severe disabilities. From SHIPPS in Maine to the

Hawaii Integration Project many different programs found ways to integrate children and young people with "severe disabilities" into regular public school settings.

For example, the authors (or their colleagues) found such practices as the following:

*A number of high school students in Providence, Rhode Island, labelled "severely emotionally disturbed" and previously in a mental health facility, attend a regular high school;

*Michael (of our earlier profile) goes to a neighborhood school. For lunch and other activities, including art, music and a reading group, Michael participates (if only partially at times) with typical children who are his own age.

*Lunchtime for Peggy (also from our profile) occurs in an elementary school gym, with about 125 typical school children. It is noisy and confusing, but Peggy sits in her adaptive chair on the end of one of the portable tables, being fed by an aide, with the help of a peer tutor some days.

*An 18 year-old student in a wheelchair attends a public high school in the midwest and spends part of each school day working in a public cafeteria. He learns to fold napkins and helps to set tables in a commercial cafeteria as part of his education.

*In the upper midwest, two high school age students are pushed around a local supermarket; shopping means matching pictures in their school-produced booklet with labels on jars and various packages. Such a shopping activity is a vital part of their "school" curriculum.

*In a regular elementary school in the South, a consulting teacher shows the kindergarten teacher how to include a child labelled "multiply handicapped" into some small-group play activities. This five year-old child spends part of the day in a resource room, part in a typical kindergarten setting and is fully integrated into the recess periods and gym.

*Robert-Andrew (from the earlier profile) attends a regular high school. Little-by-little his teachers bring him out of a self-contained classroom and into the typical activities of the high school.

At a number of different schools across the country, physical integration leads to social integration. For example, in many schools, children from typical settings ask if they can be the ones to wheel or push the "special" children to lunch, recess, physical education, the bus or other activities. Because the children with severe impairments are in the regular public settings, there are the typical social interactions of "Hi, how are you?" in a familiar, matter-of-fact way. More and more, social interaction and partial participation in gym, recess, art, music, study hall and selected academics has become the rule and not the exception.

THE CHALLENGE

"It's pie in the sky."

That was the response from many teachers.

"After all, the vast majority of these kids with the more severe disabilities are still in segregated, sometimes private schools. It's business as usual."

Teachers didn't believe that it could really be done well.

Many teachers expressed surprise that in actuality -- as a matter of real, day-to-day classroom practice -- children they knew as multiply-handicapped or severely and profoundly retarded were served in quality settings which were public, typical and integrated with typical kids.

"You simply can't have as good a program."

This particular teacher worked in a segregated public school. She had taught a class for the multiply handicapped for six years.

"What you folks are talking about . . . integrated, quality programs for my kids, I doubt. After all, most of our kids are in the same places -- the same classes and rooms and buildings, with the same tasks and objectives -- that they had five years ago."

We nodded.

"It's big business serving really severely handicapped kids," she added.

In another large city school district in the northeast, we sat around in the teacher's lounge of a city-wide special school, talking with the Head Teacher of the Severe and Profound Program, along with the Principal. We talked about how children with severe disabilities were congregated together. The Principal commented that whole empires had sprung up around such special schools.

"And we're part of it," he added.

"What's so bad about that," asked the Head Teacher.

She continued.

"I think it's a lot of hype -- this business about Least Restrictive Environment and integration."

How so, we wondered.

"These kids have special needs; all the theories and ideology and belief in normalization in the world won't make the kids normal. No way . . . it's not fair to the kids or to the parents."

She paused.

"You people simply don't know what it means to educate a severely handicapped kid. I mean look at the staffing patterns alone: in most of our classes, we've got six kids; for those six, we provide a teacher, usually two aides (or a volunteer plus an aide), two or three therapists and maybe a part-time health aide or nurse. And it's just the beginning."

We asked for elaboration.

"You simply cannot provide the quality and intensity necessary in a regular class setting. It means nearly 15 minutes per day merely to get off the coats! It means 20 minutes getting to the lunch-room and at least an hour of individual feeding programs. It's an intensive one-to-one work on fine motor, gross motor, range-of-motion, whatever."

She paused.

"Don't you realize that it can take 10 minutes alone to get a child to utter a single sound? Who's got that time or skill in

the regular class? Besides, this whole setting makes sense: you've got the equipment, sinks, toilets, all in one room, with the essential support staff immediately available."

We suggested that based upon extensive site visits our staff had found something quite different . . . We started to talk about how integrated settings use therapists differently, used consultants to support regular teachers and that there were very different curriculum approaches, including more functional, community-referenced methods. She waved us aside.,

"Sure, it's a good idea -- in theory; but it's different when you work in the classroom with these kids every day. You must be realistic, after all."

We wondered about "realistic"; what did that mean?

"We've got some real sick kids here; living and dying are daily issues. It's not fair to the kids or their parents. What do most regular educators know about seizures? What if the kid chokes on his food?

The Principal had the final word.

"You couldn't possibly meet the objectives as specified in the Individual Education Plan without these intensive special services; besides, the best way to implement these services is in a specially equipped and designed setting. It makes the most sense . . . as a model."

We started to say, "but we saw it happening . . . the models are different . . . people are using special therapists as consultants . . . there's the 'transdisciplinary' model for delivery of therapy . . ." but the meeting was over. The Principal and his Head Teacher had to get back to work.

DIFFERENT MEANINGS OF EDUCATION

From our conversations with a wide range and number of teachers, we found that many teachers struggled with the same questions:

What do we teach?

How do we teach?

And where?

Some teachers felt frustrated by questions about integration; others were excited about new ideas and approaches. We heard excitement about transdisciplinary therapy, functional IEP's, parent involvement, integration strategies, vocational training and community-based training.

In part we discovered that teachers didn't just do things differently, they also had different ideas about what education means. Some talked about "treatment" and "therapy time", others about "getting kids ready" and still others about "functional skills" and "natural settings."

We found three distinctively different approaches to the meaning of education of education for severely disabled students reflected in both the words and the feeling of these conversations. Here we will call them 1) the Clinical-Treatment Perspective, 2) the Developmental Learner Perspective, and 3) the Functional Life Skills Perspective. It is important to note that many teachers use a combination of these different approaches and perspectives. But talking about them separately will, we hope, provide some helpful clarity.

The Clinical Treatment Perspective

Until very recently, the education, treatment and programming for the population of kids labelled "severely handicapped" was a record of failure and frustration, including frequent segregation, institutionalization and weak to nonexistent programming. Ten years ago the odds would be high that none of the preceding students would be in a public school. Most would not have been in any school program at all; all three students would have been candidates for a total institutional setting.

Wherever the program's actual setting, it would be dominated by a commitment to a "clinical treatment" or "therapeutic" model. Physical and occupational therapy, as well as speech therapy would be the key "treatments." Children would be taken to the various therapies outside the classroom and given individual sessions. Typically, therapists might concentrate upon range of motion, head control, balance, mouth closure. The assumption would be that once Peggy or Michael (students mentioned earlier) could have better balance or hold-up their heads, they would be able to pick-up objects, grasp toys, start to be able to feed themselves or whatever.

Assuming that either Peggy or Michael would be in any program at all, the focus would be upon "improvement" or "getting better". There would be little need for situations where these more severely handicapped youngsters interacted and mixed with typical students. The focus of the clinical "intervention" would be relatively narrow and specific: get the child to bear weight,

position the child to prepare to crawl; work on sitting or grasping or reaching. And most of these activities would be done by therapists. To "educate" a child such as Peggy -- who had significant developmental delay and cerebral palsy -- meant to "treat" some of her "deficits" and try to overcome them through regular, technical exercises.

The context for learning would be narrow, precise and therapeutic. Once the student improved (or became less atypical) then she would develop skills to cope in a less intensive (and less segregated) setting.

For example, applied to Michael (the student mentioned earlier), the approach might mean the following: if Michael has had difficulty with sitting and if a team of medical specialists decide that he has a risk of developing a bent spine, then this clinical treatment perspective would put a body brace on the child. The object of the treatment would be to correct or prevent a "bent spine." The assumption would be that once the treatment has taken effect, then that particular problem would be "cured" or at least alleviated.

Teachers often find their role to be one of caring for students in between therapy appointments. Their contribution as educators to the student's overall program is often seen as secondary to the necessary expert and technical programs provided by therapists. Teachers alone are left to find ways to integrate and coordinate several different therapeutic programs into a student's classroom day.

One of the unfortunate consequences of the "clinical treatment" approach as a way to serve students with severe disabilities is that many of the students do not get "better"; they are not cured. Many staff who had concentrated time and effort upon the elimination of certain behavior and physical problem expressed discouragement to find that after many years, the treatment has not worked. Their frustration and fatigue often creates an attitude that "nothing much can be done."

The Developmental Learner Perspective

This perspective sees the student as lagging behind in a growth process. Students are "delayed" or "behind" in development compared to the majority of students who are the same chronological age. The teacher guides growth in a particular sequence to help the student "catch up." Hopefully, the student responds by acquiring new knowledge or skills, at a faster rate. The ultimate goal is to have the student become as able as her peers -- to catch up to the norm, or at least, to narrow the distance between present performance and the norm.

As the development gap widens beyond the need for special "catch-up" sessions or temporary removal from the regular class to special help, temporary segregation from the regular settings tends to lengthen. Frequently, temporary removal from regular class becomes permanent segregation. Furthermore, the linkage between developmental delay and removal from regular settings continues. Usually the gap between children with severe disabilities and typical children widens: therefore, children with relatively severe handicaps do not "catch up" to typical children; such children remain segregated from typical children.

A real life example follows.

At a due process hearing in a mid-western State, parents had challenged their 18 year-old son's Individual Education Plan (IEP). A primary focus of the IEP was to get the 18 year-old young person (who happened to be labelled "severely handicapped") to identify the colors red, white and blue. When asked at the hearing why the young man was trying to learn his colors at age 18, his teacher replied, "Because he has a mental age of five years old and he needs to progress in sequence as a person that mental age might do."

The hearing officer asked the teacher what would happen if the young man learned the colors?

"Then we would teach him green and brown."

It may be an extreme example; yet, there's much truth in it. The dilemma it raises for the developmental approach is fundamental: what is the answer to the question, "how old is the 18 year-old severely handicapped boy with a mental age of five years old?" Too many teachers would answer as indicated in the due process hearing, "five years old." Of course, the young man happens to be 18 years-old; within the limits of his abilities, he needs to be seen and treated as 18 years old.

In Michael's case, for example, instead of putting on a body-brace and seeing whether or not such treatment worked to correct a bent spine, the developmental perspective might teach Michael to assume the correct posture. The point would be to assist muscle development and to achieve some trunk control so that Michael would be developmentally closer to the norm. With

Robert-Andrew and the problem of aggression toward others, the developmental learner perspective might focus upon returning the student to the more normative, developmental behavior, using some of the same interventions cited earlier.

Unfortunately, with each passing year, the prospect for meeting the educational goal -- whether overcoming the deficit or catching up to the norm -- gets dimmer and dimmer. Some teachers may even begin to wonder if they are teaching anything at all. Frequently, such thoughts, even when unspoken, lead teachers of the severely handicapped to feelings of fatigue, frustration and isolation.

The Whole Life/Functional Perspective

This perspective begins by seeing the student as just different -- but not too different. The educational strategy becomes this: how can we help both the student and the student's environment adapt to each other? You can accommodate differences, even very big ones, by bringing the skills the student does have into correspondence with the skills others have and use.

There were two ways people talked about the kinds of activities this perspective suggests:

1. "You find ways for a student to do those things that, if he didn't do them, someone else would have to."

For example. Michael can't tell time yet. He can't count or talk about yesterday. But he does know "time" in a functional sense: when the picture of the clock on his desk matches the clock on the wall, it is time to go to lunch or go home. Michael

may never learn to tell time the way other children do; but in a similar way, he can look at a clock and then do something because of what the clock says. No one has to come and get him.

For Michael and other students, teachers can help turn their "differences" into just different ways of doing things for themselves: for example, use snaps or velcro fasteners so no one has to zip a student's coat; or adapt doorknobs with rubber covers so that student's themselves can turn them.

It is not always easy to figure out these adaptations or accommodations. Sometimes we saw whole groups of people -- teacher, a therapist or two, a parent -- talking about and trying different ideas until a solution was found.

Sometimes a particular student won't be able to do something completely alone; making toast for breakfast might mean just pushing down the handle of the toaster; eating a meal might mean learning to swallow well enough so you can finish when everyone else does; getting dressed might mean being able to roll over at the proper time, or taking off the shoes someone else has already untied. Even learning to do little parts of things means that someone else doesn't have to do them for you.

Thinking about education this way seems to have helped teachers find new things to teach and students new things to learn. As one teacher said, "you don't <u>have</u> to wait until they are ready."

Robert-Andrew doesn't talk. He has never babbled, or even gestured very clearly. But when he points to the picture of a cup on his communication board, people know he wants a drink. No

one is sure that he understands that the picture is a cup, but he always drinks after pointing to the cup. Robert-Andrew's communication board only has ten pictures so far. Maybe he will learn some signs. Right now he has ten ways to tell people what he wants or doesn't, even if it is without words or sentences.

2. "You find ways for a student to do the kinds of things everyone else does."

For example, Peggy can't read and she has great difficulty turning the pages of a book; but she enjoys looking at the pages and likes to have someone read to her. Still, Peggy can go to the library with the other 8 year-olds and help to check out her own books. Certainly, Peggy would not use the library or the books in just the same way the other children do; but here would be a particular similarity -- an equivalence -- about the way Peggy uses the library along with the other 8 year-olds.

A principal told us, "They don't always have to be learning some specific things. It is functional just to be able to be part of the group."

going to a basketball game to enjoy the lights and noise,
riding a bus,
playing in a park,
watching airplanes

These are all ways of being part of the group.

From this functional perspective, education takes on broader meanings. In particular, we saw the education of students happening in a variety of community settings. Students learn to

do parts of jobs in restaurants and hospitals, shop in grocery stores or malls, and learn to cross streets.

The teachers who talked about education this way said something else as well. In many instances old feelings of frustration and even hopelessness had been replaced by enthusiasm. Granted, teachers continue to struggle with a lot of the same questions, but seem convinced that they will create the answers.

PUTTING PERSPECTIVE INTO PRACTICE

The challenge of making these principles work remains. We saw a lot of different ways people are trying in the programs which do integrate students with severe disabilities. The details of teaching -- including objectives, materials, schedules, data, group lessons, even teacher hall-duty -- are still developing and being refined.

Even larger details are only slowly coming into focus. In an interview with a couple of regular education teachers in the lounge area of an elementary school, both teachers commented about the importance of support.

"It has nothing to do with dumping kids in our classes; it's a whole different model really."

One of the consulting teachers to a building (and district) where the most severely handicapped students were integrated into a wide variety of typical settings, summed up a key dimension of quality.

"First, the support staff has to be in place; you can't take the special education kids out of the room and do your thing (if you happen to be a speech therapist, for example.) It's a matter of consulting with the regular staff, working with them on practical, functional activities. We asked her what else?

"It helps to be trained; you really need to have the confidence (and skills) that kids who happen to be quite severely handicapped can be educated. And I think that system-wide issues matter, here. Will a Principal be convinced that it makes good program and fiscal sense to bring back these kids with severe disabilities and put them in their local, neighborhood schools? I mean . . . in some ways it's a matter of people changing."

Some talked about values and philosophy. For example, this comment from a teacher at a cooperative district (where they had closed segregated private and segregated public settings):

"We have the basic philosophy; the Special Education Director believes in the importance of integration. And now that they see it happening, regular teachers believe it too."

A special education director in Maine put it more pragmatically:

"If we are ever going to be able to make accommodation for the severely handicapped in our communities -- long range --, we're going to have to start in our schools."

Whether it is a matter of perspective, values, pragmatics, support, system, or all of these, it is a least as one teacher put it, "a matter of people changing."

For us the most important message is that people can and do change. Indeed, school districts and, in instances, whole states have changed. Ways have been found to integrate students with severe disabilities into public settings while maintaining and extending a necessary level of quality and intensity of programming. While many struggles and ambiguities remain, students like Peggy, Michael and Robert-Andrew are going to school and learning with other kids their age.

Resources

For analysis about and discussion of integration practices and the concept of the Least Restrictive Environment, see the following publications produced by the Special Education Resource Center at Syracuse (Regional Resource Center #2):

1. "The Least Restrictive Environment: It's Application to Education"
   --Douglas Biklen

   Traces the historical, legal, professional, and socio-political development of the LRE principle. Reviews the recent research and experience with integrated schooling and identifies the key factors which can facilitate or impede integration.

2. "Public Education for Children with Severe, Profound, and Multiple Disabilities: The Least Restrictive Environment"
   --Douglas Biklen

   Answers the questions Why? Where? and How? to integrate all students with disabilities, especially those with severe/multiple disabilities. Musters all the arguments for integration and concludes that quality integrated schooling makes sense and is working.

3. "Traditional Barriers to Education Opportunity: Unserved/ Underserved Children and Young People in Special Education"
   --Steven J. Taylor and Staff

   Presents the concept that traditional barriers have made it difficult for many children/young people to get a free, appropriate education. Provides an analytical framework to understand how to overcome traditional barriers to full service. Suggests a variety of solutions.

4. "Making Integration Work: Strategies for Educating Students with Severe Disabilities in Regular Schools"
   --Steven J. Taylor

   Describes the creative practices and strategies actually being used in states, school districts, individual schools and classrooms across the country to provide integrated schooling for students with severe disabilities.

The preceding publications are available for $1.00 each for postage and handling from the Special Education Resource Center.

SPECIAL EDUCATION RESOURCE CENTER
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For background and a wide variety of effective teaching approaches, see the following:

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